Ensuring Quality ACT Programs

NAMI ACT Steering Committees, Implementation Steering Committees, and ACT Team Stakeholder Advisory Groups

Background

It is the policy of the National Alliance for the Mentally Ill, as well as the membership's strong desire, for people with the most serious, long-term mental illnesses to receive state-of-the-art, recovery-oriented services in the least restrictive settings. Therefore, the Assertive Community Treatment (ACT) model, developed in Madison, Wisconsin, has become the model of choice because ACT not only is an evidence-based practice, but it is also an effective service-delivery model for persons with more disabling schizophrenia, other psychotic disorders, and bipolar disorders. The ACT multidisciplinary team provides a range of the most effective treatment services as well as dual diagnosis/substance abuse services, practical help with employment and housing, and support for solving the everyday problems that are significant barriers to independence.

However, as NAMI members learned more about the ACT model, they found that it was not available across the nation; and, where it was in place, it had not necessarily been implemented well. In many places, it had been modified or changed and often looked like traditional mental health services, an ACT program in name only.

In 1996, NAMI began an initiative to stimulate national dissemination of the ACT model. The NAMI National Assertive Community Treatment Technical Assistance (TA) Center was established in 1998 with support from the Center for Mental Health Services to make ACT services available to all persons with severe and persistent mental illnesses whose needs are not met in traditional mental health programs. As the ACT TA Center collaborated with state NAMI organizations and local affiliates to respond to the need for quality ACT programs, they learned that successful implementation of ACT-model programs is greatly enhanced by 1) organizing steering committees to work with state, county, and local governments and managed care organizations; and 2) by requiring Stakeholder Advisory Groups that support and monitor individual ACT teams.

In this process, NAMI found that the ACT Steering Committees and Stakeholder Advisory Groups are an effective way to get ACT to the decision-making tables in states, counties, and cities. In addition, involving community Stakeholders in the process of improving services for persons with the most severe and persistent mental illnesses makes ACT implementation a "larger community" project and draws in people who can support the mental health system to make it happen.

How the Idea Started

The idea for Steering Committees and Stakeholder Advisory Groups started in Iowa. Magellan Behavioral Care of Iowa, a behavioral health managed care organization in that state, asked consumers and families to be a part of an advisory committee to help plan and evaluate services for persons with severe and persistent mental illnesses. NAMI

Iowa welcomed this invitation to come to the decision-making table to represent people with severe and persistent mental illnesses and to promote their ideas about effective service delivery that is acceptable to clients and families. Because NAMI Iowa had studied the ACT model for many years, they were excited about this opportunity to join with Magellan to bring ACT to their state.

As Magellan's advisory committee began meeting, the working relationship and collaboration among the managed care organization, the state, consumers, families, and providers grew and prospered. The advisory committee studied the ACT model, participated in developing the financing plan, supported the use of the Request For Proposal (RFP) process to select the first ACT programs, and planned for training and evaluating the new programs. The success of the Stakeholder collaboration led to Magellan's requiring in the RFP that each new ACT team have a local Stakeholder advisory group consisting of 51 percent consumers and families to support and monitor ACT implementation.

Magellan is also the managed care entity for Tennessee. Here, Magellan is known as AdvoCare. NAMI Tennessee had formed an ACT Steering Committee that included representatives from the local NAMI affiliates across the state and had studied ACT to bring program fidelity to Tennessee's early ACT development. AdvoCare's working relationship and collaboration with NAMI Tennessee's ACT Steering Committee led again to an ACT RFP process, building on Iowa's RFP, and again required that the providers establish local Stakeholder advisory groups. *(See Figure 12-1 on the next page.)*

In both states, consumers and family members were part of the RFP process. Their activities ranged from participating in the development of the RFP, speaking at bidders' meetings about ACT and why consumers and families want programs with fidelity to the ACT model; serving on the RFP review committee; and being involved in the first consultation and training of the new teams. Consumers and family committee members offered bidders ideas about how to recruit members for the ACT Stakeholder Advisory Groups, and the members that sat on the RFP review committees were instrumental in the evaluation of each proposal's plan for the ACT Stakeholder Advisory Group. In fact, the RFP question asking how the provider would go about setting up an advisory group and the requirement that potential members provide letters of support proved to be very helpful when assessing the provider agency's philosophy and attitude about serving persons with severe mental illnesses and their families.

Three Types of Advisory Groups Working Together

Increasing the quality and relevance of community mental health services—especially for those with severe and persistent mental illnesses—requires a dedicated, motivated group of people who work together to first determine unmet needs and then advocate for superior services. ACT Steering Committees and ACT Team Stakeholder Advisory Groups do both. The three types of advisory groups are:

NAMI ACT Steering Committee

An ACT Steering Committee within a NAMI state organization (or within a county or city NAMI affiliate) motivates and guides the NAMI organization and teaches the members how to effectively advocate for assertive community treatment teams. The committee is a resource for both local NAMI groups and other mental health organizations because it can explain and promote ACT and provide complete information about these programs. During internal discussions, committees share ACT information so that members' points are consistent when they present their needs to funding sources, other organizations, and the media.

An ACT Steering Committee consists of a small group of people who are determined to make ACT their advocacy priority. Steering Committee leaders, often NAMI members, want and accept a leading role in introducing ACT to their state or community or in helping existing ACT teams improve to meet national standards. Membership may be statewide or groups focused on a single county or city. Mental health consumers are an integral part of ACT Steering Committees initially and throughout all activities. Whenever possible, a NAMI Consumer Council representative serves on the committee.

Figure 12-1: Tennessee Request for Proposals

AdvoCare of Tennessee, Inc., Request for Proposals: Requiring Stakeholder Advisory Groups

Consumer and Family Involvement

Under the terms of the contract resulting from this RFP, each PACT* team will be required to identify and convene a PACT Advisory Committee to ensure that the program is implemented properly and in a timely manner. The Advisory Committee will be actively involved in the implementation and ongoing program-evaluation process, and will also advise on and monitor issues of client complaints and grievances, as well as on client rights. Membership should consist of at least 51 percent consumers and family members.

A. Please provide the names of persons whom you have identified to serve on your PACT Advisory Committee. Which program staff member will serve as liaison to the committee? Include a brief biography for each proposed committee member, together with a letter of support.

B. How does your agency propose to involve the advisory committee in program implementation and management?

C. Whom will the advisory committee report to within your organization?

D. Please describe your Client Complaints and Grievance process.

E. Are there other ways you propose to involve consumers and family members in the start-up, ongoing operations, and evaluation of your proposed PACT program? If so, please describe.

Source: TennCare Program of Assertive Community Treatment Program Initiative, August 1999.
**ACT teams in Tennessee are referred to as PACT teams.*

Implementation Steering Committee

The Implementation Steering Committee helps state, county, and local governments and managed care organizations implement ACT programs. The ACT Implementation Steering Committee may consist of state, county, and local mental health administrators, NAMI ACT Steering Committee members, other consumers and family representatives, and advocacy groups. Sometimes they also include managed care representatives, provider organization or association staff, legislators, and representatives from other departments (e.g., corrections, vocational rehabilitation, Medicaid, housing). The Implementation Steering Committee is usually chaired by someone in the department of mental health, but members of the state NAMI organization or another entity may initiate and/or chair this committee.

ACT Team Stakeholder Advisory Group

The ACT Team Stakeholder Advisory Group supports and guides individual ACT team implementation and operation. Each ACT team has a Stakeholder Advisory Group whose membership consists of 51 percent mental health consumers and family members. The membership also includes community Stakeholders who interact with persons with severe and persistent mental illness (homeless services, food-shelf agencies, faith-based entities, the criminal justice system, the housing authority, landlords, employers, and community colleges). In addition, group membership represents the local cultural populations.

The Stakeholder Advisory Group's primary function is to promote quality ACT programs, monitor fidelity to the ACT Standards, guide and assist the administering agency's oversight of the ACT program, problem-solve and advocate to reduce barriers to ACT implementation, and monitor/

review/mediate client and family grievances or complaints. The Stakeholder Advisory Group promotes and ensures clients' empowerment and their recovery values in assertive community treatment programs. *The National Standards for ACT Teams, June 2003,* requires that each ACT team have a Stakeholder advisory group.

The Stakeholder Advisory Group is independent of, but communicates directly with, management staff in the agency sponsoring the team. The ACT team leader and other staff participate in the Stakeholder Advisory Group meetings upon the request of the group. The ACT team, or its sponsoring agency, provides administrative support to the Stakeholder group.

Strategies for ACT Steering Committees and Stakeholder Advisory Groups

Attaining Sufficient Consumer and Family Representation

*C*onsumer and family leadership has done more for ACT-model dissemination and implementation than anything else to date. Consumer and family representation in sufficient numbers (51 percent) at the planning table is essential 1) to ensure that their voice is heard and that people who need ACT services have priority; 2) to evaluate the effectiveness of the current mental health services for people with severe and persistent mental illnesses; 3) to advocate for evidence-based recovery-oriented services as the standard, not the exception; and 4) to monitor and evaluate ACT implementation and effectiveness.

Forming Coalitions

Involving members of the larger community on ACT Steering Committees and Stakeholder Advisory Groups is an important strategy to broaden understanding of severe mental illnesses and to increase awareness that severe mental illnesses are treatable disorders. Mental health has typically not been a public health concern or a concern of community developers charged with making the community a place where all people enjoy living. Opening membership to form coalitions is an effective means of involving members of the larger community and gaining their support for the need for evidence-based ACT services for persons with the most severe and persistent mental illnesses. Their support will become an advocacy tool for reaching important audiences. Broadening the base of support for mental health is also important to combat societal stigma and to increase support for a state-of-the art mental health system. Poor-quality services are unacceptable in other types of health care; therefore, poor-quality services are unacceptable for people with the most disabling forms of mental illness.

Knowing the ACT Model

Knowing the ACT model is essential for members of Steering Committees and Stakeholder Advisory Groups. In fact, this manual was originally written to provide detailed information about the ACT model so that NAMI consumer and family members could have a working knowledge about ACT and understand the research results. The second purpose of the manual was for them to have something to hand to people in the mental health system when state administrators or providers thought what they were operating was ACT, when in fact what was offered was more a maintenance approach rather than the ACT rehabilitation approach. Reading the manual, getting expert consultation, and visiting well-functioning ACT teams are among the ways Steering Committees and Stakeholder Advisory Groups prepare themselves for introducing ACT to the state and local mental health systems. It is not uncommon for Steering Committee Members and Stakeholder Advisory Group members to be more knowledgeable about ACT than professionals in the mental health system. But it is essential for them to know as much as possible about ACT to teach it, to help with implementation, and to monitor and evaluate ACT-model fidelity and client outcome.

NAMI Oklahoma provides a good example. They successfully helped start six ACT teams in Oklahoma. *See Figure 12-2 on the next page.*

Successful ACT implementation and demonstrated improvements in client outcome are best accomplished by close adherence to the ACT model's focus on serving persons with the most severe and persistent mental illnesses; multidisciplinary staffing

Figure 12-2: Steering Committees and Stakeholder Advisory Groups Focus on Close Adherence to the ACT Model

NAMI Oklahoma Steering Committees and Stakeholder Advisory Groups

as documented by Oscar Kastner, NAMI Tulsa

NAMI Oklahoma Statewide Steering Group

The members of this committee are all NAMI members.

A. Purpose

1. to help the state Department of Mental Health and Substance Abuse Services to develop a PACT*-implementation plan;
2. to advocate for PACT funding by the state legislature;
3. to inform the general public by submitting articles to the news media; and
4. to search for, inform, and seek funds from potential PACT providers.

B. Activities

1. to bring PACT experts to the state to inform members of the state legislature;
2. to provide PACT Start-Up Manuals to potential PACT providers;
3. to assess the need for PACT services in the state; and
4. to advocate for the program until it is actually started.

Statewide PACT Implementation Committee

In Oklahoma, the Department of Mental Health and Substance Abuse Services PACT specialist chairs this committee. Members include NAMI representatives, PACT team leaders, members of the state legislative staff, a representative from the state health care authority (Medicaid), a representative from the Department of Rehabilitation Services, a representative from the Department of Corrections, and other interested Stakeholders.

A. Purpose

1. to monitor PACT team development;
2. to monitor faithfulness of services to the National Standards for ACT Teams; and
3. to plan for and promote continued expansion of the PACT program until PACT services are available throughout the entire state.

B. Activities

1. to hold periodic meetings. In Oklahoma, meetings were monthly for the first year, and then bi-monthly; and
2. to offer recommendations to the Department of Mental Health and Substance Abuse Services.

Local PACT Team Advisory Committees

Membership of the local PACT Team Advisory Committees is usually between 10 and 15, including a minimum of 51 percent NAMI consumer and family members (which includes at least three consumers) and other community Stakeholders. In Tulsa, members are from the Day Center for the Homeless, the police department, the Mental Health Association, and the business community; and one is an attorney.

A. Purpose

1. to monitor fidelity of services to the National Standards for ACT Teams;
2. to publicize the PACT program in the community;
   a. to promote appropriate referrals of clients to the PACT team;
   b. to help to solve problems; and
   c. to monitor development of the team to reach its full capacity.

B. Activities

1. to hold periodic meetings. In Tulsa, the meetings were monthly and then bi-monthly; and
2. to report to the statewide PACT Implementation Committee.

** ACT teams in Oklahoma are referred to as PACT teams*

with at least one peer specialist; low staff-to-client ratios and intensive services; face-to-face availability weekdays and evenings, weekend days and holidays, and availability for 24-hour on-call services; team organizational and communication structure; client-centered, individualized assessment and treatment planning; and up-to-date, individually tailored treatment, rehabilitation, and support services based on the original Madison, Wisconsin, PACT research.

Understanding Financing

Because ACT is a self-contained clinical team made up of a multidisciplinary mental health staff, including a peer specialist, who work together to provide the majority of the treatment, rehabilitation, and support services clients need to achieve their goals, it requires careful analysis and planning to determine how to pay for it. Just as important as knowing the ACT model thoroughly is learning as much as possible about how mental health services are paid for or financed (e.g., general purpose revenue; Medicaid; Medicare; federal mental health block grant; local tax revenue, fees) in a given state or locality.

Figuring out what is needed for program start-up, constructing the ACT budget, and evaluating potential sources for funding are important when working with the state mental health authority and Medicaid to establish an ACT benefit. Medicaid is a major source for funding ACT. All State Medicaid Directors received a letter in June 1999 from the Center for Medicaid and State Operations encouraging them to consider including in their plans comprehensive approaches to community-based mental health service based on ACT. In order for State Medicaid Directors to fund ACT, the state has to put it in the State Medicaid Plan.

Funding may have to come from redeploying funds from programs that are not effective or efficient. In addition, ACT work-related services may be paid for by vocational rehabilitation agencies. The Steering Committee and Stakeholder Advisory Group members can be of great assistance in the process of determining how to pay for ACT.

Starting ACT Programs Incrementally and Evaluating Client Outcome

Starting one demonstration program has proven to be a manageable and effective way to bring ACT to a state, county, and locality. "A test run" identifies the particular issues involved in starting up ACT programs and can provide a "road map" for implementing future ACT programs. Concentrated attention and support are required from the upper management of the provider agency, the state mental health authority, and the advisory group to start an ACT team (e.g., hiring the staff with a peer specialist position, scheduling staff to work shifts and provide on-call services, setting up the office, arranging for transportation) and to set up ACT program evaluation. In fact, it is necessary to have a full-time staff position dedicated at the state or county level to serve as the ACT program manager and direct implementation.

In addition, a demonstration program helps a state or locality to identify the clients who most need the ACT program, to make sure the program is available to them, and to ensure that clients are admitted gradually (four to six per month). It also helps state mental health and provider agency administrators to really understand that the ACT client-centered approach is quite different than traditional services and must be implemented step-by-step.

Demonstration programs save time in the long run by providing necessary and valuable experience before attempting to set up other programs statewide. The involvement of Implementation Steering Committees and ACT Team Stakeholder Advisory Groups is critical to learning how ACT can be implemented in their community. Advisory groups can help identify and problem-solve the myriad of challenging issues (e.g., lack of housing, union rules that staff can only work weekdays, agency policy that forbids staff to transport clients) that are encountered in starting up ACT programs.

Establishing program evaluation of both client outcome (e.g., quality housing, employment, symptom reduction, satisfaction with services) and fidelity to the ACT model needs to be developed with the first ACT team. Designing and field-testing the evaluation process is an important activity that can be more easily accomplished by starting with one

team. It is important for the Steering Committees and the Stakeholder Advisory Group to ensure that clients are achieving the expected outcomes and meeting their personal goals. It is critical that the steering committees, advisory group, and everyone involved is sure that clients are no longer living in board-and-care homes, but in apartments, and that clients are working and have social opportunities. The Steering Committees and the Stakeholder Advisory Group assist in reviewing the data collected and interpreting the results.

Making the best use of what is learned when starting the first ACT team, paves the way for future ACT team development; and, if possible, the ACT demonstration program may become a training site for new ACT teams.

Supporting ACT Teams with Expert Consultation and Training

The Steering Committees and Stakeholder Advisory Groups advocate for ACT teams to receive ongoing consultation and training from experienced ACT consultants throughout the first two to three years of program operation. The ACT client-centered approach cannot be taught or learned by didactic training alone, but requires side-by-side consultation and mentorship. Steering Committee and Stakeholder Advisory Group members are involved in choosing the consultants, participating in the consultation and training, and supporting and monitoring ACT team progress in implementing what they learn through consultation and training.

Checklist for Steering Committees and Stakeholder Advisory Groups

How Steering Committees and Stakeholder Advisory Groups spend the majority of their time will depend on what is needed in each particular situation. However, the most important activities include the following:

- introduce ACT to the state, county, or local mental health system, to the behavioral health managed care organizations, and to legislators;
- promote quality ACT programs that meet the National Standards for ACT Teams;
- advocate for adequate funding and resources for the ACT team;
- actively participate with the administering agencies in step-by-step program implementation;
- problem-solve and advocate to reduce system barriers to ACT implementation such as lack of affordable housing, lack of support from upper-level management, and limited public transportation;
- monitor and review client and family grievances or complaints; and
- promote and ensure that ACT staff provide clients the respect and hope that leads to recovery and a productive, satisfying life.

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